Published in final edited form as:

Ann Epidemiol. 2016 June ; 26(6): 441–446.e3. doi:10.1016/j.annepidem.2016.04.006.

Self-reported herpes zoster, pain, and health care seeking in the Health and Retirement Study: implications for interpretation of health care–based studies

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Abstract

Purpose—To describe self-reported herpes zoster (HZ) and explore factors that could impact interpretation of results from health care–based HZ studies.

Methods—We performed logistic regression using data from the 2008 Health and Retirement Study (HRS) to evaluate risk factors for having a history of HZ and experiencing severe HZ pain, and predictors for seeking health care for HZ.

Results—Among 14,564 respondents aged ≥55 years, women were more likely than men to report a history of HZ (15.7% vs. 11.6%, $P < .01$). Blacks (6.4% vs. 14.7% in whites, $P < .01$) and respondents with less than a high school diploma (12.2% vs.14.2% in respondents with at least a high school diploma, $P = .01$) were less likely to report a history of HZ. Women, blacks, Hispanics, and those with less than a high school diploma were more likely to report severe HZ pain. Most (91.1%) respondents sought health care for HZ; Hispanics (64.2% vs. 92.1% in whites, $P < .001$) and those with recurrent HZ were less likely to seek health care for HZ, whereas those with severe pain were more likely (95.4% vs. 87.9% in those without severe pain, $P < .01$).

Conclusions—HRS provides a new platform for studies of HZ, one which allowed us to uncover issues that warrant particular attention when interpreting results of health care–based studies.

Keywords

Herpes zoster; Health surveys; Epidemiologic methods; Population surveillance; Risk factors; Pain; Health care seeking behaviour; Medical records

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No authors have a commercial or other association that might pose a conflict of interest.

Disclaimer: The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Background

Herpes zoster (HZ) is a painful and often debilitating illness that affects about 1 million Americans annually [1]. Although most adults have been latently infected with the varicella zoster virus [2] and are therefore at risk for HZ, the incidence of HZ increases sharply after age 50. Older adults also bear a disproportionately heavy burden of HZ complications, with >80% of postherpetic neuralgia occurring in adults aged 50 years and older [1].

Electronic health records and health care claims provide convenient sources of data that allow longitudinal studies of large populations that would otherwise be too expensive and impracticable. We owe much of our understanding of HZ epidemiology to studies using such data sources [1,3–12]; however, it is unknown if differences in health care–seeking behavior affect observed differences in HZ risk with respect to age, sex, or race or ethnicity reported from studies using these data sources. We also do not understand the extent to which health care data capture the full spectrum of HZ illness, for example, mild or recurrent HZ cases. The objective of this study is to describe self-reported HZ, acute HZ pain severity, and health care seeking for HZ in a nationally representative survey of adults ≥50 years of age. Using this novel platform, we provide independent estimates of HZ incidence, evaluate risk factors for HZ without being subject to differences in health care–seeking behavior and explore factors that could impact interpretations of results from health care encounter-based HZ studies.

Materials and methods

We performed a cross-sectional analysis of the 2008 wave of the Health and Retirement Study (HRS), a nationally representative panel survey of community-dwelling adults aged 50 years or older, with oversampling of black and Hispanic persons [13]. In 2008, all respondents were asked a series of questions about their history of HZ, HZ-related pain, and whether they sought health care for HZ. Most interviews were by telephone, although some respondents had face-to-face interviews if they had health limitations that would make a long conversation on the telephone difficult or impossible, or when there was no telephone in the household. Because the youngest respondents in the 2008 wave entered the study in 2004 at age 50 years, nearly all respondents were aged ≥55 years at the time of interview; we excluded the few who were aged <55 years.

We conducted a separate validation study comparing self-reported HZ to Medicare claims for HZ among a subset of 5194 respondents in the 2008 wave for whom such data were available (see appendix A for detailed methods and results). Respondents have the option of being interviewed in either Spanish or English, regardless of the language they speak on a daily basis. We found very low agreement ($\kappa = 0.08$) between self-reported HZ and having a Medicare claim for HZ among respondents who were interviewed in Spanish; therefore, we excluded these respondents throughout the main analysis. We also performed a sensitivity analysis that included respondents interviewed in Spanish.

We evaluated the effect of sex, age at the time of interview, race or ethnicity, and education level on having a history of HZ using responses to the question “Have you ever had

shingles?" A definition of shingles was provided for respondents who had difficulty understanding the survey item (see appendix B). Respondents reporting a history of HZ were asked "How many times have you had shingles?" and "How old were you when you (last) had shingles?"

For evaluating acute HZ-related pain and health-seeking behavior, we defined a subpopulation of respondents who reported an episode of HZ within the last 5 years (age at the time of interview minus 5) to reduce recall error.

We evaluated the effect of sex, age at the time of HZ, race or ethnicity, prior lifetime episodes of HZ, and education level on self-reported severe HZ pain using responses to the question: "Using a scale from 0 to 10, with 0 being "no pain" and 10 being "pain as bad as you can imagine", please rate the shingles pain you experienced by indicating the number that best describes your shingles pain when it was at its worst," a question adapted from the Zoster Brief Pain Index [14]. Self-reported worst-pain score has been shown to have a strong correlation with interference in activities of daily living and quality of life. We defined severe HZ-related pain as a score of 8 or higher. Because the most severe pain generally occurs in the acute phase of HZ disease [15,16] and respondents were not asked about duration of HZ-related pain, we assume that the worst-pain score reported by respondents reflects acute HZ-related pain.

We evaluated the effect of sex, age at the time of interview, race or ethnicity, prior lifetime episodes of HZ, severe HZ-related pain, education level, and current health insurance status on seeking health care for the most recent episode of HZ, using responses to the question: "Did you see a doctor or other health care provider for your last episode of shingles?"

Statistical analysis

We used logistic regression models to evaluate the relationship of sex, age, race or ethnicity, education level, and other factors with having a history of HZ, severe HZ-related pain, and seeking health care for HZ. In addition to unadjusted and adjusted odds ratios, we report predictive margins ("standardized percentages"), a type of direct standardization that allows us to compare predicted outcomes between groups in the population (e.g., females vs. males) from a logistic regression model controlling for differences in the distributions of other covariates (e.g., age group, race or ethnicity, and so forth) among those groups [17,18]. We report *P* values for the difference in standardized percentages. Results are weighted to represent the U.S. community-dwelling population 55 years of age or older.

Analyses were performed using SAS (version 9.3; SAS Institute, Inc., Cary, NC) and SUDAAN (version 11; Research Triangle Institute, Research Triangle Park, NC) to account for the complex survey design.

The HRS is under Institutional Review Board approval by the University of Michigan and the National Institute on Aging. All HRS data used in this analysis are publically available. We obtained Medicare claims data for the validation study through data use agreements with University of Michigan and the Centers for Medicare and Medicaid Services.

Results

The 2008 wave had an 88.4% survey response rate [19] and consisted of 15,649 community-dwelling adults. We excluded 255 respondents <55 years of age at the time of interview, and 766 respondents who were interviewed in Spanish. Respondents interviewed in Spanish had a lower education level (77% had less than a high school diploma vs. 19% of those interviewed in English) but were similar to those interviewed in English with respect to sex and age. We also excluded 64 respondents with missing data on education level or history of HZ, leaving 14,564 respondents in the analysis. Their demographic characteristics are shown in Table 1.

We estimate that in 2008, 13.8% (95% confidence interval [CI], 13.0–14.7) of U.S. adults 55 years of age or older had a history of HZ, ranging from 10.1% in 55–59-year olds to 23.8% in those 85 years of age and older (Table 2, unadjusted). In a multiple logistic regression model including sex, age at the time of interview, race or ethnicity, and education level (Table 2), women were more likely to report a history of HZ than men (15.7% vs. 11.6%, $P < .01$). Blacks were less likely to report a history of HZ compared with whites (6.4% vs. 14.7%, $P < .01$) and those with less than a high school diploma reported a history of HZ less frequently than those with at least a high school diploma (12.2% vs.14.2%, $P = .01$).

Of all respondents, 5.4% (95% CI, 4.9–5.9) reported an episode of HZ within 5 years before the interview. Of the 815 respondents who reported HZ within 5 years, the median worst HZ-related pain score was 6.2 (interquartile range, 3.6–8.3), with 40.9% reporting severe pain (95% CI, 37.2–44.7), defined as a pain score of at least 8 on a scale of 0 to 10. In a multiple logistic regression model including sex, age at the time of HZ, race or ethnicity, previous episodes of HZ, and education level, more women reported severe pain compared to men (44.2% vs. 34.9%, $P = .04$). Blacks (63.9%) and Hispanics (62.3%) reported severe pain more often than whites (38.8%, P values for blacks and Hispanics <.01 and .03, respectively) and a greater proportion of those with less than a high school diploma reported severe pain than those with at least a high school diploma (53.3% vs. 38.1%, $P < .01$). Age at the time of HZ and previous episodes of HZ were not associated with severe HZ-related pain (Table 3).

Of the same 815 respondents, 91.1% reported seeing a health care provider for HZ (95% CI, 88.2–93.3). In a multiple logistic regression model including sex, age group, race or ethnicity, prior episodes of HZ, education level, severe HZ-related pain, and insurance status, Hispanics were less likely to report seeking health care for HZ compared to non-Hispanic whites (64.2% vs. 92.1%, $P < .01$; Table 4). Those who reported 2 or ≥3 episodes in their lifetime were less likely to visit a health care provider for the most recent episode compared with those with only a single episode. Those reporting severe HZ-related pain were more likely to seek health care (95.4% vs. 87.9%, $P < .01$). There was no significant difference in seeking health care by sex, age group, education level, or insurance status.

In a sensitivity analysis that included the 766 respondents interviewed in Spanish ($n = 15,330$), estimates from regression models of a history of HZ, severe HZ-related pain, and

seeking health care were minimally changed, except that Hispanic respondents were less likely to report a history of HZ compared with whites (8.5% vs. 14.6%, $P < .01$).

Discussion

We used HRS to provide the largest population-based assessment of HZ and sociodemographic risk factors to date, providing information that is independent of health care–seeking behavior and access to health care. These self-reported data also allow us to better understand the experience of HZ, which we cannot readily do using health care encounter data, including the risk for and predictors of severe, acute HZ pain. Importantly, we found that–with important exceptions–persons experiencing HZ generally receive care for the condition, thereby supporting much of the epidemiology that we have learned about HZ from on health care–based studies.

The validation study comparing self-reported HZ with Medicare claims for HZ showed very poor agreement among respondents who were interviewed in Spanish ($\kappa = 0.08$). A global survey of public awareness of HZ found that only 30% of Mexican residents aged ≥50 years reported that they had ever heard of shingles compared to the global median of 84% [20]. Low agreement between self-reported HZ and Medicare claim for HZ may be due to low awareness of shingles disease or of the Spanish translation of HZ (both “culebrilla” and “herpes zóster” were used); however, a previous survey found no significant difference in HZ incidence among Hispanics interviewed in English or Spanish [21]. Overall, agreement among respondents interviewed in English was good ($\kappa = 0.71$). Agreement was somewhat lower among respondents interviewed in English who were of Hispanic ethnicity ($\kappa = 0.51$) or had been diagnosed with a memory problem ($\kappa = 0.47$), although still within κ values of 0.40 to 0.75, which represent fair to good agreement [22]. Only respondents of other race or ethnicity had a κ value < 0.40.

There are limitations in using Medicare claims as the “gold standard” for validation purposes. A diagnosis of HZ is most often made clinically without laboratory confirmation and misclassification with herpes simplex is possible. Furthermore, billing codes used for medical claims do not always accurately represent the clinical diagnosis; for example, HZ codes may indicate a history of HZ, current postherpetic neuralgia, or that HZ is being considered as part of a differential diagnosis [23]. Agreement depended on self-reported HZ occurring when the respondent was enrolled in Medicare, although dates of Medicare enrollment and claims used in this study were offset randomly to protect identification of the beneficiary, which could increase error. Moreover, respondents could have sought care not captured by Medicare claims, such as with a traditional or alternative healer. A previous study [24] comparing self-reported HZ with actual medical record review showed much higher agreement ($\kappa = 0.98$). Notwithstanding these limitations, the validation study identified certain respondent characteristics where self-reported HZ did not accurately reflect the respondent’s actual history of HZ. The validation study did not assess validity of responses about HZ-related pain or health care seeking; however, the fact that estimates from the sensitivity analyses of HZ-related pain and health care seeking, which included respondents interviewed in Spanish, were essentially the same as the main analyses, which excluded those respondents, indicates that interview language had no substantial effect on

the relationship between respondent characteristics and either HZ-related pain or health care–seeking for HZ.

Returning to the main analysis, our finding that 23.3% of respondents aged 85 years or older reported a lifetime history of HZ is comparable with studies using health care data, which have estimated the lifetime risk of HZ as 10%–20% [25] and more recently as approximately 30% [1,3,26]. A survey of 3206 persons in North Carolina also found a lifetime risk of HZ of approximately 19% in whites and 8% in blacks aged >85 years [27]. Our finding of lower rates of HZ in black persons is consistent with previous reports [11,12,28,29]. The 5-year incidence of 5.4% is consistent with published estimates [1].

We found that 41% of respondents with recent HZ experienced severe acute pain with an intensity of at least 8 of 10 at its worst, highlighting the potential of HZ to limit activities of daily living and decrease quality of life. This finding represents a nationally representative estimate of HZ pain intensity that is more generalizable compared with studies where participants enroll after presenting for health care and compared with vaccine trials where participants are not representative of the entire population. Black and Hispanic persons reported severe HZ pain almost twice as frequently as whites. The level of acute HZ-related pain by race or ethnicity is seldom reported, although one study showed a higher, but not statistically significant, pain burden among nonwhite persons compared with whites [30]. Studies of disparities in non-HZ acute pain among racial and ethnic minorities report differences in pain perception and tolerance among black and Hispanic persons, as well as undertreatment of pain in these populations by health care providers [31]. Early antiviral treatment has been shown to reduce acute HZ pain, and medications such as non-steroidal anti-inflammatory drugs, opioids, anticonvulsants, and others are commonly used to treat acute HZ pain [32]. Our finding of increased severity of acute HZ pain among females [33,34] and persons with lower education level [30] have been previously reported. We found no association between increasing age and severe acute HZ pain; previous studies have shown either small [33,34] or no [15,30,35] association of acute pain with increasing age. HRS did not assess duration of HZ-related pain; therefore, we could not evaluate the potentially devastating effect of postherpetic neuralgia on quality of life.

Over 91% of respondents with HZ reported seeking medical attention, a finding consistent with previous surveys [36–38] reporting that 95%–96% respondents with HZ sought care and provides reassurance that epidemiologic studies of HZ based on health care data capture most HZ cases in the study population. We also found that those with severe HZ-related pain were more likely to report seeking health care, suggesting that health care–based studies may preferentially capture clinically significant HZ cases. In contrast, clinical trials attempt to capture all cases of HZ, even mild cases for which the subject may not otherwise seek health care. Differences in HZ ascertainment between clinical trials and studies using health care data could lead to different estimates of effects of interventions such as vaccines [11,39].

Health care–seeking by Hispanics should be considered when interpreting results from health care–based studies. We found that Hispanics more frequently reported severe HZ-related pain and that respondents who reported severe pain were more likely to seek health

care; however, even after adjusting for the effect of severe pain on seeking health care, Hispanics were still less likely to seek care for HZ compared to whites. Factors other than income or insurance status can affect use of health services by older American minorities, such as intrinsic care-seeking behavior, beliefs about the medical system, and views of care providers [40]. A potential consequence is that Hispanics may present with more severe HZ compared to other race or ethnic groups when they do seek health care. HZ incidence in Hispanics is rarely reported, but a lower incidence in Hispanics compared to whites calculated using health care claims has been published [12]. On the contrary, our analysis showed similar rates of self-reported HZ in whites and Hispanics.

Most, but not all, previous health care–based studies [1,6–8,11,21,28,29,41,42] of HZ incidence have reported higher incidence in women. This study found that a higher proportion of women self-reported a history of HZ and that women and men were similarly likely to seek care, thus supporting the conclusion that women do have a higher risk of HZ compared with men, and this finding is not an artifact of a greater tendency by women to seek health care.

Respondents with recurrent HZ were less likely to seek health care, suggesting that studies of recurrent HZ using health care data may underestimate the true risk of recurrent HZ. Respondents with less than a high school diploma were less likely to report a history of HZ, unlike two previous studies that showed no association [21,27]. Respondents with lower educational level may have lower health literacy and may not have recognized HZ when it appeared or may not have understood the interview question; alternatively, education level may be correlated with some other unmeasured confounder.

This study has certain limitations. Although 96% of adults ≥55 years of age have heard of shingles [43], correct self-identification of HZ also depends on having some knowledge of the signs and symptoms of HZ or being diagnosed by a healthcare provider; therefore, some HZ cases may not have been recognized and, conversely, some illnesses may have been incorrectly identified by the respondent as HZ. More than 90% of respondents who reported a history of HZ saw a healthcare provider, who presumably confirmed the diagnosis. A diagnosis of HZ is generally made clinically and not confirmed by laboratory testing; therefore, some misclassification with similar rash illnesses such as herpes simplex is possible, especially in persons reporting multiple episodes. We cannot estimate how many respondents failed to recognize the signs and symptoms of HZ and decided not seek health care, although we expect this number to be small, given the acute and painful nature of the disease. Recall error is a concern in any survey, but we attempted to minimize recall error by restricting analyses of HZ-related pain and health care seeking to respondents who reported HZ in the last 5 years; however, it is unknown if differential recall related to severe pain or complications may bias these results. Finally, current insurance status is an imperfect measure of insurance coverage during the entire 5 years before the interview.

Conclusion

HRS provides a new platform for population-based studies of HZ, independent of health care–seeking behavior and access to health care, and provides information not readily

available in health care data, such as severity of HZ pain and health care–seeking behavior. It is reassuring that findings from HRS and the body of health care–based studies agree to a large extent on risk factors such as sex and race or ethnicity; this is not unexpected given that the vast majority of those who self-reported HZ also accessed the health care system for care. Ascertainment bias relating to health care utilization is a potential threat to the validity of health care-based studies for a wide variety of acute and chronic diseases. Corroborating the findings of such studies using non-health care-based sources is warranted. HRS allowed us to uncover issues that warrant particular attention when interpreting results of health care–based studies, including under-reporting of HZ in Hispanics and under-representation of less severe and recurrent HZ cases.

Acknowledgments

The authors thank Barbara Bardenheier, PhD, MPH, MA, and William S. Pearson, PhD for their valuable methodologic expertise and assistance.

Funding: No external funding was obtained for this study.

Appendix A

Validation study of self-reported herpes zoster using Medicare claims

We performed a study to validate self-reported herpes zoster (HZ) among respondents in the 2008 wave of the Health and Retirement Study (HRS). All Medicare-eligible HRS respondents are asked for permission to access their records from the Centers for Medicare and Medicaid Services. We compared self-reported HZ among Medicare beneficiaries in the HRS with their linked Medicare claims.

HRS respondents included in this validation study met the following criteria: (1) the respondent was 65 years of age or older, was enrolled in fee-for-service Medicare parts A and B at the time of the interview, had at least 1 month of continuous enrollment in parts A and B, and had linked Medicare records available for analysis; and (2) responses to interview questions given by respondent him/herself and not a proxy (If a respondent is not able to give an interview due to poor health condition or cognitive status, a proxy, usually a close family member, responds to interview questions on his/her behalf).

For purposes of validation, we defined self-reported HZ as follows: (1) the respondent reported a history of only one or two episodes of HZ; (2) the age at which one or both cases were reported to have occurred fell within the period of continuous Medicare enrollment; and (3) the respondent reported seeking health care for their last episode of HZ. We compared respondents who met this definition of self-reported HZ with those who reported never having an episode of HZ.

We defined a health care visit for HZ as the presence of an *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM), code (any position) for HZ (053.xx) in any health care setting (outpatient, inpatient, skilled nursing facility, and home health settings) during a period of continuous Medicare parts A and B enrollment up to and including the date of the interview. We excluded HZ codes that occurred within 7 days of the

occurrence of a Current Procedural Terminology code for HZ vaccination (90736) [1]. We excluded individuals with an ICD-9 code for postherpetic neuralgia (053.12 or 053.13) without any other HZ code during the period of continuous enrollments because this may represent a case of HZ that occurred in the past.

We calculated kappa statistics to measure agreement between Medicare claims and self-reported HZ. Kappa statistics between 0.40 and 0.75 reflect fair to good agreement; kappa statistics below this rage reflect poor agreement and those above this range reflect excellent agreement [2]. We also calculated sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV) for self-reported HZ, using the presence of a health care visit for HZ as the gold standard for convenience of analysis and interpretation of results. We evaluated agreement by several respondent characteristics: sociodemographic characteristics, cognitive ability, physical health, supplementary health insurance, health care utilization, time since last HZ, and length of continuous Medicare enrollment. We also evaluated agreement by language in which the interview was conducted. Respondents may elect to have the interview conducted in Spanish. The item “Have you ever had shingles?” was translated as “¿Ha tenido alguna vez culebrilla (herpes zóster/shingles)?” A definition of shingles was provided for respondents who had difficulty in understanding the survey item (see Appendix B).

SAS (version 9.3; SAS Institute, Inc., Cary, NC) was used for data management, and data analysis was performed using SUDAAN (version 11; Research Triangle Institute, Research Triangle Park, NC) to account for the complex survey design. All results are weighted to the community-dwelling U.S. population unless indicated otherwise.

Table

Kappa, sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV) for self-reported herpes zoster (HZ) by respondent characteristic

Characteristic	Unweighted *n* (%)	Sensitivity	Specificity	PPV	NPV	Kappa
Sex						
Male	2099 (42.1)	67.9	98.5	77.9	97.6	0.71
Female	2888 (57.9)	68.5	98.1	80.5	96.4	0.71
Age group (y)						
65–74	2504 (50.2)	77.5	98.8	77.6	98.8	0.76
75–84	1832 (36.7)	64.9	97.8	81.0	95.0	0.68
85+	651 (13.1)	65.0	97.6	79.1	95.2	0.68
Race/ethnicity						
White (non–Hispanic)	4170 (83.6)	68.8	98.2	80.0	96.8	0.71
Black (non–Hispanic)	601 (12.1)	67.2	99.4	83.1	98.5	0.73
Hispanic *	132 (2.6)	59.7	96.7	48.5	97.9	0.51
Other	84 (1.7)	28.9	99.3	59.4	97.6	0.38
US-born						
No	246 (4.9)	82.8	98.5	80.6	98.7	0.80
Yes	4740 (95.1)	67.7	98.3	79.5	96.8	0.71

Characteristic	Unweighted *n* (%)	Sensitivity	Specificity	PPV	NPV	Kappa
Education level						
Less than high school diploma	2941 (59.0)	67.3	98.3	80.7	96.5	0.71
High school diploma or higher	2045 (41.0)	70.1	98.3	77.8	97.4	0.72
Income (quartile)						
1st	1133 (22.7)	59.7	98.9	84.2	96.0	0.67
2nd	1270 (25.5)	75.4	97.8	78.6	97.4	0.75
3rd	1340 (26.9)	73.3	98.1	81.5	97.0	0.75
4th	1244 (24.9)	62.0	98.3	73.5	97.2	0.65
Total assets (quartile)						
1st	1123 (22.5)	57.7	98.3	70.8	97.1	0.61
2nd	1277 (25.6)	68.8	98.3	82.1	96.4	0.72
3rd	1296 (26.0)	76.5	97.9	82.7	96.9	0.77
4th	1291 (25.9)	62.7	98.6	77.1	97.2	0.67
Lives alone						
No	3510 (70.4)	67.7	98.4	78.2	97.3	0.70
Yes	1477 (29.6)	69.2	98.0	81.5	96.1	0.72
Usually speaks English at home						
No	113 (2.3)	73.0	98.3	63.9	98.9	0.67
Yes	4757 (97.7)	68.5	98.2	80.0	96.8	0.71
Interview mode						
Face–to–face	3197 (64.1)	68.5	98.3	81.9	96.5	0.72
Telephone	1790 (35.9)	67.8	98.2	73.9	97.6	0.69
Veteran status						
No	3589 (72.0)	69.3	98.2	79.1	97.0	0.71
Yes	1396 (28.0)	65.7	98.6	81.9	96.8	0.71
Military health plan†						
No	4517 (90.7)	69.0	98.4	80.2	97.0	0.72
Yes	463 (9.3)	62.7	97.3	73.9	95.6	0.64
Private primary plan‡						
No	4790 (96.0)	68.5	98.3	79.6	97.0	0.71
Yes	197 (4.0)	64.1	97.8	78.5	95.6	0.67
Self–reported doctor visits in last year						
0–3 visits	1243 (24.9)	64.2	98.5	80.6	96.6	0.69
4–6 visits	1298 (26.0)	75.1	98.4	81.6	97.7	0.76
7–11 visits	1429 (28.7)	61.3	98.4	78.0	96.5	0.66
12 + visits	1017 (20.4)	73.2	97.6	78.1	96.9	0.73
Diagnosed memory problem§						
No	4817 (96.6)	69.1	98.3	79.9	97.0	0.72
Yes	170 (3.4)	40.6	98.4	66.0	95.5	0.47
Self–reported memory‖						
Poor	1528 (30.6)	66.1	97.7	74.3	96.7	0.67
Fair	2180 (43.7)	64.2	98.6	81.8	96.5	0.70

Characteristic	Unweighted *n* (%)	Sensitivity	Specificity	PPV	NPV	Kappa
Good	1279 (25.6)	77.6	98.3	81.9	97.8	0.78
Cognitive impairment[¶]						
Mod/severe	262 (5.3)	45.1	100	100	94.5	0.60
Mild	976 (19.6)	54.6	98.2	71.6	96.3	0.59
None	3749 (75.2)	72.6	98.2	80.3	97.2	0.74
Self–reported health						
Excellent	383 (7.7)	76.4	98.9	85.4	98.1	0.79
Very good	1412 (28.3)	74.1	98.6	82.4	97.7	0.76
Good	1727 (34.7)	64.3	97.9	75.6	96.4	0.67
Fair	1016 (20.4)	68.3	98.2	79.6	96.8	0.71
Poor	446 (8.9)	61.2	98.4	81.7	95.6	0.67
# of Chronic diseases[#]						
0	890 (17.9)	61.0	99.2	87.8	96.4	0.70
1	1865 (37.5)	72.7	98.1	80.6	97.1	0.74
2	1422 (28.6)	66.2	98.0	74.7	97.0	0.68
3	578 (11.6)	66.0	98.3	79.4	96.7	0.70
4–6	216 (4.3)	75.5	96.9	73.5	97.2	0.72
Moderate physical activity						
At least once per month	3723 (74.7)	70.9	98.4	80.1	97.4	0.73
Hardly ever or never	1261 (25.3)	62.5	97.9	78.4	95.5	0.66
Years of continuous Medicare enrollment						
0–2 y	547 (11.0)	60.4	99.8	86.7	99.2	0.71
3–5 y	910 (18.2)	79.8	99.4	84.4	99.2	0.81
6–10 y	1508 (30.2)	76.3	97.5	71.7	98.0	0.72
>10 y	2022 (40.5)	64.6	97.8	82.5	94.4	0.69
Years since last Medicare claim HZ						
0–2 y	175 (40.5)	78.6	—	—	—	—
3–5 y	104 (24.1)	64.3	—	—	—	—
6–10 y	114 (26.4)	62.1	—	—	—	—
>10 y	39 (9.0)	52.4	—	—	—	—
Severe HZ–related pain[**]						
No	212 (56.4)	—	—	78.2	—	—
Yes	164 (43.6)	—	—	81.2	—	—
Years since most recent self-reported HZ						
0–2 y	161 (42.7)	—	—	84.4	—	—
3–5 y	104 (27.6)	—	—	84.2	—	—
6–10 y	80 (21.2)	—	—	72.7	—	—
>10 y	32 (8.5)	—	—	—	—	—

[*] Includes only Hispanics who were interviewed in English.

[†] Currently covered by TRI-CARE, CHAMPUS, CHAMP-VA, or any other military health care plan.

[‡] Self-reported enrollment in a private health insurance plan, which is considered primary.

[§] A doctor has told the respondent he/she had a memory-related disease.

[//] Response to the question “How would you rate your memory at the present time?”

[¶] Based on cognitive testing performed during the interview [3].

[#] Total number of the following self-reported chronic diseases: high blood pressure, diabetes, cancer, lung disease, stroke, psychiatric disorder.

[**] Reported HZ-related pain when it was at its worst with an intensity score of at least 8 on a scale of 0 (no pain) to 10 (pain as bad as you can imagine).

Of 10,810 respondents aged 65 years or older in the 2008 wave, 5194 (48%) met the criteria for inclusion in the validation study. This sample represents a population of 17.6 million community-dwelling Medicare beneficiaries. The validation study cohort had a mean age of 75.7 years, with 57.9% female, 87.1% white, 6.6% black, 4.3% Hispanic, and 2.0% other race or ethnicity, and did not differ substantially from all HRS respondents aged 65 years or older with respect to these characteristics. Median length of continuous enrollment in Medicare parts A and B was 8.4 years (interquartile range, 4.3 to 14.8 years; range, 1 month to 16.9 years).

An initial analysis found that respondents who were interviewed in Spanish had markedly lower agreement compared with respondents interviewed in English, with kappa of 0.08, sensitivity of 8%, specificity of 98%, PPV of 21%, and NPV of 94%. Because of the very low agreement and potential confounding with analysis of other respondent characteristics such as Hispanic ethnicity, we excluded 207 respondents who were interviewed in Spanish. The results presented below and in the table were calculated from the 4987 respondents who were interviewed in English.

Overall agreement was good, with kappa of 0.71, sensitivity of 68%, specificity of 98%, PPV of 80%, and NPV of 97%. The table shows kappa, sensitivity, specificity, PPV, and NPV by several respondent characteristics. These measures were similar by sex, age, country of birth, education level, HZ-related pain severity, living alone, interview mode (face-to-face vs. telephone), veteran status or having a military health plan, having a private health insurance plan that was primary (i.e., Medicare was secondary), number of self-reported health care visits in the last year, overall self-reported health, number of chronic diseases, amount of physical activity, and years of continuous Medicare enrollment.

Hispanic respondents (kappa = 0.51, sensitivity = 59.7%, PPV = 48.5%) and those of other race or ethnicity (kappa = 0.38, to sensitivity = 28.9%, PPV = 59.4%) had lower agreement compared white (kappa = 71, sensitivity = 68.8%, PPV = 80.0%) and black (kappa = 0.73, sensitivity = 67.2%, PPV = 83.1%) respondents. Respondents who reported not usually speaking English at home also had a somewhat lower PPV compared to respondents who reported usually speaking English at home (63.9% vs. 80.0%).

Although agreement was similar regardless of the self-reported memory, agreement was lower in respondents who reported being diagnosed with a memory problem (kappa = 0.47 vs. 0.72, sensitivity = 40.6 vs. 69.1, PPV = 66.0 vs. 79.9). Sensitivity decreased among respondents with mild (54.6%) or moderate/severe (45.1%) cognitive impairment compared with respondents with no impairment based on testing performed during the interview.

Sensitivity decreased by time since most recent Medicare claim for HZ (52.4% for >10 years vs. 78.6% for 1–2 years) and PPV decreased by time since most recent self-reported HZ (59.6% for >10 years vs. 84.4% for 0–2 years).

Respondents interviewed in Spanish had very poor agreement between self-reported HZ and having a Medicare claim for HZ. Shingles was translated as “culebrilla”, although HRS staff reported that not all Spanish speakers were familiar with this word; therefore, the medical term “herpes zóster” and the English term “shingles” were added to the question (personal communication). Sensitivity and PPV were both very low, indicating that a large proportion of respondents who had a health care visit for HZ responded “no” to the question “¿Ha tenido alguna vez culebrilla (herpes zóster/shingles)?” and a large proportion of respondents who responded “yes” to this question did not have a health care visit for HZ.

Among respondents interviewed in English, those who reported not usually speaking English at home often reported a history of HZ without having a Medicare claim for a HZ visit, and Hispanics and those of other race or ethnicity had lower agreement, suggesting some misinterpretation of the term “shingles” or differences in understanding of the disease itself. Respondents had similar agreement regardless of whether they were born in the United States.

This analysis excluded interviews with proxy respondents to evaluate the influence of the respondent’s cognitive function on agreement of HZ reported by the respondent him/herself; however, an initial analysis showed high agreement among interviews with proxy respondents (kappa = 0.78).

Appendix B

Text of Health and Retirement Study item on history of shingles in English and Spanish

Definition of shingles for respondents who had difficulty understanding the survey item “have you ever had shingles?”

“Shingles generally occurs only in adults, usually older adults. It is a painful rash that usually occurs only on one side of the body, usually on the trunk. It can occur on the face and less often on the legs. There is pain, burning, numbness, or extreme sensitivity. Usually, there are fluid-filled blisters that crust over. People with shingles are often sick, with fever and chills, and headache. It may take several weeks for shingles to heal, and it may recur. The pain may last longer than the rash.”

For interviews conducted in Spanish, the definition of shingles for respondents who had difficulty understanding the survey item “¿Ha tenido alguna vez culebrilla (herpes zóster/shingles)?”

“La culebrilla (herpes zóster/shingles) generalmente ocurre únicamente en adultos, usualmente en adultos de edad mayor. Es un sarpullido doloroso que típicamente se da en un lado del cuerpo, por lo general en el tronco del cuerpo. Puede presentarse en la cara y con menos frecuencia en las piernas. Hay dolor, ardor, adormecimiento o extrema sensibilidad

en el cuerpo. Usualmente aparecen ampollas con líquido que llegan a formar costras. Las personas con culebrilla generalmente tienen fiebre, escalofríos y dolor de cabeza. Puede tomar varias semanas para que la culebrilla (herpes zóster/shingles) se cure, y es posible que vuelva a reaparecer. Es posible que el dolor dure más que el sarpullido.”

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Table 1

Characteristics of Health and Retirement Study (HRS) respondents 55 years of age or older, 2008 (n = 14,564)

Characteristic	*n*	%, weighted*
Female	8410	54.5
Age group, y		
55–59	2312	27.4
60–64	2015	21.1
65–69	2892	15.5
70–74	2668	11.9
75–79	2005	10.0
80–84	1382	7.6
85+	1290	6.4
Race or ethnicity		
White (non-Hispanic)	11,418	84.3
Black (non-Hispanic)	2139	9.2
Hispanic	679	3.9
Other	328	2.6
Education level		
Less than high school diploma	3409	19.2
High school diploma or higher	11,155	80.8

*Weighted to represent the U.S. community-dwelling population.

Table 2

History of herpes zoster among U.S. adults 55 years of age or older (n = 14,564)

Characteristic	Unadjusted odds ratio (95% CI)	Adjusted odds ratio (95% CI)	Standardized % (95% CI)*	P**
Sex				
Male	reference	reference	11.6 (10.7–12.6)	reference
Female	1.47 (1.31–1.65)	1.43 (1.27–1.61)	15.7 (14.5–16.9)	<.01
Age† group, y				
55–59	reference	reference	10.2 (9.0–11.6)	reference
60–64	1.10 (0.89–1.36)	1.09 (0.88–1.35)	11.1 (9.6–12.7)	.42
65–69	1.35 (1.09–1.66)	1.35 (1.09–1.66)	13.3 (11.6–15.2)	<.01
70–74	1.63 (1.37–1.93)	1.60 (1.35–1.90)	15.4 (13.9–17.1)	<.01
75–79	1.88 (1.55–2.29)	1.85 (1.52–2.26)	17.3 (15.5–19.5)	<.01
80–84	2.34 (1.93–2.83)	2.28 (1.88–2.76)	20.5 (18.6–22.4)	<.01
85+	2.76 (2.29–3.32)	2.63 (2.17–3.18)	22.8 (20.4–25.7)	<.01
Race or ethnicity				
White (non-Hispanic)	reference	reference	14.7 (13.8–15.6)	reference
Black (non-Hispanic)	0.37 (0.31–0.44)	0.39 (0.34–0.46)	6.4 (5.5–7.5)	<.01
Hispanic	0.70 (0.51–0.96)	0.82 (0.60–1.13)	12.4 (9.4–16.3)	.19
Other	0.70 (0.46–1.08)	0.76 (0.49–1.18)	11.7 (7.9–16.9)	.18
Education level				
Less than high school diploma	reference	reference	12.2 (10.7–13.9)	reference
High school diploma or higher	1.14 (0.99–1.31)	1.20 (1.04–1.38)	14.2 (13.4–15.1)	.01

CI = confidence interval.

*Standardized percentages are the predictive margins from a logistic regression model including all other covariates in the model.

**P for difference in standardized % compared to the reference group.

†Age at the time of interview.

Table 3

Severe herpes zoster (HZ)-related pain (worst pain rated ≥8 or higher on a scale of 0 to 10) among U.S. adults 55 years of age or older with a history of HZ within 5 years of the interview (n = 815)

Characteristic	Unadjusted odds ratio (95% CI)	Adjusted odds ratio (95% CI)	Standardized % (95% CI)*	P**
Sex				
Male	reference	reference	34.9 (28.1–42.3)	reference
Female	1.67 (1.14–2.45)	1.51 (1.01–2.25)	44.2 (39.7–48.9)	.04
Age† group, y				
50–59	reference	reference	39.5 (30.7–49.0)	reference
60–69	1.07 (0.64–7.81)	1.04 (0.60–1.80)	40.4 (33.7–47.4)	.89
70–79	1.30 (0.83–2.04)	1.23 (0.75–2.01)	44.2 (39.6–49.0)	.41
80+	1.01 (0.58–1.75)	0.95 (0.50–1.80)	38.4 (28.4–49.5)	.87
Race/ethnicity				
White (non-Hispanic)	reference	reference	38.8 (34.7–43.0)	reference
Black (non-Hispanic)	3.32 (1.80–6.12)	2.89 (1.50–5.54)	63.9 (49.4–76.3)	<.01
Hispanic	2.69 (1.06–6.85)	2.69 (1.05–6.85)	62.3 (40.3–80.2)	.03
Other	1.16 (0.34–3.96)	1.18 (0.33–4.22)	42.6 (18.6–70.7)	.80
# lifetime episodes of Herpes Zoster				
1	reference	reference	40.4 (36.4–44.6)	reference
2	1.12 (0.64–1.97)	1.15 (0.63–2.09)	43.6 (30.6–57.4)	.65
≥3	1.02 (0.57–1.82)	1.05 (0.59–1.86)	41.5 (30.1–54.0)	.87
Education level				
Less than high school diploma	reference	reference	53.3 (45.9–60.5)	reference
High school diploma or higher	0.48 (0.33–0.69)	0.53 (0.37–0.77)	38.1 (33.9–42.6)	<.01

HZ = herpes zoster; CI = confidence interval.

*Standardized percentages are the predictive margins from a logistic regression model including all other covariates in the model.

**P for difference in standardized % compared to the reference group.

†Age at the time of most recent episode of HZ.

Table 4

Seeking health care for herpes zoster (HZ) among U.S. adults 55 years of age or older with a history of HZ within 5 years of the interview (n = 815)

Characteristic	Unadjusted odds ratio (95% CI)	Adjusted odds ratio (95% CI)	Standardized % (95% CI)*	P**
Sex				
Male	reference	reference	87.8 (81.9–92.0)	reference
Female	1.71 (0.85–3.47)	2.02 (0.91–4.48)	92.8 (89.4–95.2)	.10
Age† group, y				
50–59	reference	reference	90.9 (84.0–95.0)	reference
60–69	1.41 (0.58–3.45)	1.44 (0.56–3.73)	93.1 (89.2–95.7)	.46
70–79	1.43 (0.65–3.12)	1.05 (0.41–2.66)	91.2 (86.6–94.4)	.92
80+	0.83 (0.32–2.17)	0.47 (0.17–1.28)	84.4 (75.3–90.6)	.14
Race/ethnicity				
White (non-Hispanic)	reference	reference	92.1 (89.2–94.2)	reference
Black (non-Hispanic)	0.89 (0.27–2.97)	0.65 (0.17–2.48)	89.0 (72.3–96.2)	.58
Hispanic	0.33 (0.13–0.85)	0.11 (0.04–0.27)	65.8 (51.3–77.8)	<.01
Other	1.10 (0.13–9.32)	0.74 (0.07–7.98)	90.0 (56.0–98.5)	.82
Lifetime episodes of herpes zoster				
1	reference	reference	95.2 (92.5–97.0)	reference
2	0.34 (0.17–0.65)	0.25 (0.11–0.54)	84.5 (75.1–90.7)	<.01
≥3	0.11 (0.05–0.24)	0.07 (0.03–0.18)	64.9 (51.0–76.7)	<.01
Education level				
Less than high school diploma	reference	reference	93.0 (86.7–96.4)	reference
High school diploma or higher	0.50 (0.24–1.04)	0.70 (0.30–1.64)	90.8 (87.7–93.1)	.37
HZ-related pain				
Pain (0–7)	reference	reference	87.9 (83.5–91.3)	reference
Pain (8–10)	2.60 (1.17, 5.74)	3.41 (1.47–7.88)	95.4 (91.8–97.5)	<.01
Insurance status				
No insurance	reference	reference	88.9 (62.2–97.5)	reference
Some type of insurance	2.78 (0.86–8.98)	1.37 (0.19–9.64)	91.2 (88.3–93.4)	0.77

CI = confidence interval.

*Standardized percentages are the predictive margins from a logistic regression model including all other covariates in the model.

**P for difference in standardized % compared to the reference group.

†Age at the time of most recent episode of HZ.